Problem Solving in Patient-Centred and Integrated Cancer Care

You treat a disease, you win, you lose. You treat a person, I guarantee you, you'll win, no matter what the outcome.

Hunter Doherty 'Patch' Adams, MD (American physician, author and social activist)

Problem Solving in Patient-Centred and Integrated Cancer Care

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Contents

Contributors viii
Preface xiii
Acknowledgements xiv
Abbreviations xv

SECTION ONE **Perspectives**

1. Patient-Centred and Integrated Cancer Care, *Peter Selby, Ruth E. Board, Galina Velikova* 1
2. Monitoring of Symptoms, Toxicity and Functioning Using Patient-Reported Outcome Measures, *Alexandra Gilbert, Peter Selby, Galina Velikova* 6
3. Assessment of Psychological Distress in Cancer, *Jane Younger* 14
4. Patient-Centred Decision Making: Communication Challenges, *Lesley Fallowfield, Peter Selby* 19
5. Patient Engagement and Empowerment: Key Components of Effective Patient-Centred Care, *Hugh Butcher, Peter Selby* 24
6. How Can the GP Support the Patient through the Whole Cancer Journey? *Sinead Clarke, Pete Nightingale, Anthony Cunliffe* 31
7. Making a Difference: the True Value of Voluntary Sector and NHS Collaboration for Cancer Patients, Carers and Families, *Laura Lee* 36
8. Cancer Survivorship, *Lynn Calman, Claire Foster* 39
9. Survivorship and Rehabilitation: Recommendations from a European Perspective, *Tit Albreht, Christine Berling, Claudia Ferrari, Stein Kaasa, Luzia Travado* 45
10. Improving Quality of Life after Cancer Treatment, *Jane Maher, Lesley Smith, Louisa Petchey* 50
11. Integration of Palliative Care Support into Oncology Practice, *Lucy Ziegler, Michael I. Bennett* 58
12. Integration of Supportive Care into Oncology Clinics Ensures Best Practice for Patients with Metastatic Cancer, *Tracey Coleby, Lorraine Turner, Andrew M. Wardley* 61
13. Integration of Cancer Care between Primary Care and Hospitals, *Peter Selby, Geoff Hall, Ladislav Dusek, Fotios Loupakis, Lucio Luzzatto, Tit Albreht, Richard D. Neal, Rob Turner, Sean Duffy* 64

14. Psychosexual Difficulties after Cancer, *Isabel White, Justin Grayer* 71

15. Social Difficulties of Cancer Patients, *Penny Wright, Peter Selby* 78

16. Complementary Therapies in Patient-Centred and Integrated Cancer Care, *Jacqui Stringer* 83

17. Fertility Issues in Cancer Treatment, *Rebecca Lee, Anne Armstrong* 87

18. Embedding Patient and Public Involvement and Engagement in a Cancer Research Centre, *Jim Fitzgibbon, Kate Cleary, Annmarie Nelson* 92

SECTION TWO **Case studies**

1. A Young Adult with Sarcoma: a Case of Complexities, *Anna Olsson-Brown, Jane Younger* 97

2. Cancer of Unknown Primary Treated with Palliative Chemotherapy and Hospice Care, *Nicola Hughes, Daniel Swinson, Emma Lowe* 102

3. A Patient with Advanced Oesophageal Cancer Requiring Interventional Radiology and Palliative Care Input, *Mark Openshaw, Sam Khan, Meera Chauhan, Laura Clipsham, Anne Thomas* 106

4. A Metastatic Breast Cancer Patient Who Was Suicidal and Refused Treatment, *Kok Haw Jonathan Lim, Bethan Daniel, Tracey Coleby, Andrew M. Wardley* 112

5. Metastatic Adenocarcinoma of the Lung, *Vinton Cheng, Denis Talbot* 117

6. Lessons Learnt from a Deaf Patient with Ovarian Cancer, *Nicola Flaum, Jurjees Hasan* 124

7. A Young Man with Undiagnosed Autistic Spectrum Disorder and Hodgkin's Lymphoma, *Alexandra R. Lewis, Kim Linton* 129

8. A T3N1 Oesophageal Adenocarcinoma Patient Refusing Curative Surgery for Seemingly Irrational Reasons, *Maung Maung Myat Moe, Clare Kane, Cate Simmons, Lucinda Melcher* 134

9. A Patient with Brain Cancer: from Diagnosis to Treatment, *Yin Zhou* 139

10. A Woman Presenting to Primary Care with Painful Bone Metastases, *Lucy Flanders, Mulyati Mohamed, Pauline Leonard* 144

11. Management of Psychological and Behavioural Challenges in a Patient with Glioblastoma, *Suryanarayana Kakkilaya, Jane Younger* 149

12. Psychological Therapy to Aid Tablet Taking in Cancer Treatment, *Lesley Seddon, Fiona James, Ruth E. Board* 153

13. Treatment Challenges in a Patient with Metastatic Breast Cancer, *Helen Adderley, Elena Takeuchi* 159

14. Treatment of Cervical Cancer during Pregnancy and Management of Late Effects, *Alexandra Gilbert, Kate Cardale, Galina Velikova* 163

15. A Patient with Prostate Cancer with Ureteric Obstruction and Complex Social Issues, *Charlotte Richardson, Iva Damyanova* 169

16. Integrated Care When Cancer Is Diagnosed in Pregnancy, *Richard Simcock, Pete Wallroth* 173

17. Integrated Care in the Treatment of Head and Neck Malignancy, *Siobhan Morrison, Andrew Fishburn, Anne Carter, Rachel Hewitson, Katy Everson, Muthiah Sivaramalingam* 177

18. Vulvovaginal Pain after Breast Cancer Treatment, *Josie Butcher* 182

19. Use of Patient-Reported Outcome Measures to Enhance Follow-Up after Germ Cell Tumour Treatment, *Oana C. Lindner, Dulani Ranatunge, Dan Stark* 188

20. A Young Woman with Advanced Gastric Cancer, *Gemma Dart, Alison Young* 196

21. A Patient with Metastatic Breast Cancer, *Alicia-Marie Conway, Elena Takeuchi* 201

22. A Patient with Melanoma, Severe Psychosis on Steroids, and Multiple Other Issues, *Hariharan Kuhan, Gail Prout, Paul Nathan* 205

Index **210**

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Preface

The great strides that have been made in cancer care and the technologies that surround cancer screening, diagnosis and treatment are important and well recognized. They have contributed to the radical improvements in cancer survivorship seen in recent decades across much of the world. It is, however, equally important to emphasize the advances that have been made in approaches to ensure that a person who is undergoing diagnostic investigations or cancer treatments, or who is a survivor of cancer, is kept at the centre of all activities. We have improved our knowledge of how to involve patients at all stages and ensure they achieve the best experience, well-being and quality of life. This book describes the progress we have made and the efforts that must continue to strengthen this patient-centred approach. In our attempts to do justice to this very broad subject, we have involved multi-professional teams as authors of both the perspective chapters and the case reports. The teams who have developed and edited this book, and who have written the individual contributions, include not only oncologists and patients but also psychologists, psychiatrists, nurses and allied health professionals, as well as a wide-ranging mixture of senior and junior people from the many professions.

To achieve the best patient-centred care, it is important to integrate the efforts of many disciplines, professions and institutions. Cancer care becomes increasingly complex and reaches across primary, secondary, tertiary and social care, requiring the interactions of many healthcare institutions in every sector. The importance of integrating specialized multidisciplinary cancer care through cancer networks and other arrangements has been recognized for more than two decades, but opportunities to improve integration and to ensure that it supports patient-centred care continue to grow. Perhaps most notably, modern health informatics provides us with excellent opportunities to integrate the care of cancer patients between disciplines, professions and institutions with the minimum of disruption to patients' lives. Increasingly, it will be possible to move information rather than patients around the healthcare system, allowing care to be delivered in an integrated way close to patients' homes for much of the time. Of course, important periods of time will continue to be needed in specialist facilities for the delivery of appropriate aspects of patient care.

This book is part of a prize-winning annual series of books on key topics in cancer care that are important to patients and professionals alike and that are growing, developing and shaping future approaches.

Galina Velikova, Lesley Fallowfield, Jane Younger, Ruth Board and Peter Selby, Editors
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Galina Velikova, Lesley Fallowfield, Jane Younger, Ruth Board and Peter Selby

Association of Cancer Physicians

The *Problem Solving* series of cancer-related books is developed and prepared by the Association of Cancer Physicians, often in partnership with one or more other specialist medical organizations. As the representative body for medical oncologists in the UK, the Association of Cancer Physicians has a broad set of aims, including education for its own members and for non-members, including interested clinicians, healthcare professionals and the public. The *Problem Solving* series is a planned sequence of publications that derive from a programme of annual scientific workshops initiated in 2014 with 'Problem Solving in Acute Oncology' followed by 'Problem Solving in Older Cancer Patients', 'Problem Solving Through Precision Oncology' and, most recently, 'Problem Solving in Patient-Centred and Integrated Cancer Care'.

The publications involve considerable work from members and other contributors; this work is done without remuneration, as an educational service. The books have been well received and we are delighted with their standard. *Problem Solving in Older Cancer Patients* and *Problem Solving Through Precision Oncology* were awarded the BMA prizes for best oncology book of the year in 2016 and 2017, respectively.

The Association of Cancer Physicians wishes to thank all the contributors to this and previous books and to those yet to come.

Johnathan Joffe, Chairman, Association of Cancer Physicians

Abbreviations

ABVD	Doxorubicin, bleomycin, vinblastine, dacarbazine
ADT	Androgen deprivation therapy
AFP	Alpha-fetoprotein
Akt	Protein kinase B
ALK	Anaplastic lymphoma kinase
BRAF	Serine/threonine-protein kinase B-Raf
BSL	British Sign Language
CAM	Complementary and alternative medicine
CanCon	Joint Action on Cancer Control
CBT	Cognitive behavioural therapy
CCCN	Comprehensive cancer care network
CEA	Carcinoembryonic antigen
CK	Cytokeratin
CQUIN	Commissioning for quality and innovation
CRP	C-reactive protein
CRPC	Castrate-resistant prostate cancer
CTCAE	Common terminology criteria for adverse events
DART	Distress Assessment and Response Tool
dCRT	Definitive chemoradiotherapy
EGFR	Epidermal growth factor receptor
EPF	European Patients' Forum
ER	Oestrogen receptor
FDG	Fluorodeoxyglucose
FIGO	International Federation of Gynecology and Obstetrics
FISH	Fluorescence *in situ* hybridization
FOLFOX	Fluorouracil, folinic acid, oxaliplatin
GCSF	Granulocyte-colony stimulating factor
hCG	Human chorionic gonadotrophin
HER2	Human epidermal growth factor receptor 2
HNA	Holistic needs assessment
HRQOL	Health-related quality of life
IVADO	Ifosfamide, vincristine, dactinomycin, doxorubicin
LDH	Lactate dehydrogenase
LHRHa	Luteinizing hormone-releasing hormone analogue
MAPK	Mitogen-activated protein kinase
MDT	Multidisciplinary team
MEK	Mitogen-activated protein kinase kinase
NCSI	National Cancer Survivorship Initiative
NSCLC	Non-small-cell lung carcinoma
OxMdG	Oxaliplatin, fluorouracil, folinic acid
pCR	Pathological complete response
PD-L1	Programmed death-ligand 1
PPIE	Patient and public involvement and engagement
PR	Progesterone receptor
PROMs	Patient-reported outcome measures
PS	Performance status
PSA	Prostate-specific antigen
QOL	Quality of life
RANKL	Receptor activator of nuclear factor kappa-B ligand
SACT	Systemic anticancer therapy
SDI-21	21-item Social Difficulties Inventory
TKI	Tyrosine kinase inhibitor
TPN	Total parenteral nutrition
TTF-1	Thyroid transcription factor 1
TYA	Teenage and young adult
VIDE	Vincristine, ifosfamide, doxorubicin, etoposide

We would like to dedicate the book to
Mike Baum, Ken Calman, Jim Till and Peter Maguire.

01 Patient-Centred and Integrated Cancer Care

Peter Selby, Ruth E. Board, Galina Velikova

Introduction

The delivery of cancer care must focus on ensuring the best outcomes and experience for the patient by drawing on the wide range of skills of the multidisciplinary team (MDT). These are a combination of clinical and technical skills, together with good communication, empathy and involvement of the patient in all aspects of care planning and delivery. Patient-centred care necessitates excellence in the quality and speed of diagnostic work and in the delivery of treatment, follow-up and long-term support. It requires control of the tumour and the best possible patient survival. We must also optimize health-related quality of life (HRQOL), patient experience and patient satisfaction with care. The best clinical options should be identified, preferably by a specialized MDT. The options are then considered with the patient, the family and carers. Decisions must take into account the views of both the healthcare professionals and the patient. Delivering excellent patient-centred care requires good communication skills. Patient participation in shared decision making, patient empowerment, and patient engagement in individual care, service planning and research all contribute to driving excellent patient-centred care.

The terminology in this area is rightly constantly evolving. 'Patient-centred care' is widely used to describe these aspects of cancer care, and we have used the term in this book. We recognize, however, that as the field extends to include approaches to people who undergo screening tests and diagnostic investigations, and as cancer survivors take up the reins of their lives again, the term 'person-centred care' becomes increasingly appropriate. This book brings together colleagues from a wide range of healthcare disciplines to articulate their understanding of patient-centred care, how to deliver it and how to consolidate its position in cancer care systems. A key aspect of developing and delivering excellent patient-centred care is the collaboration between many professions and disciplines. Integration of care can improve outcomes for cancer patients and is especially important to ensure a patient-centred approach.

Commitments to patient-centred care have been in place for several decades. An early example in the UK lay in the 1995 Calman–Hine report,[1] which said: 'The development of cancer services should be patient-centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communication between professionals and patients is especially important.' These concepts are brought up to date and elegantly expressed by Abrahams *et al.*[2] (Figure 1.1).

Key challenges

Excellence in patient-centred care has many challenges. Patient outcomes have many aspects, and assessing them requires increasingly complex outcome measures, often patient-reported outcome measures (PROMs) (see Chapter 2). Psychological and social factors are key aspects of patients'

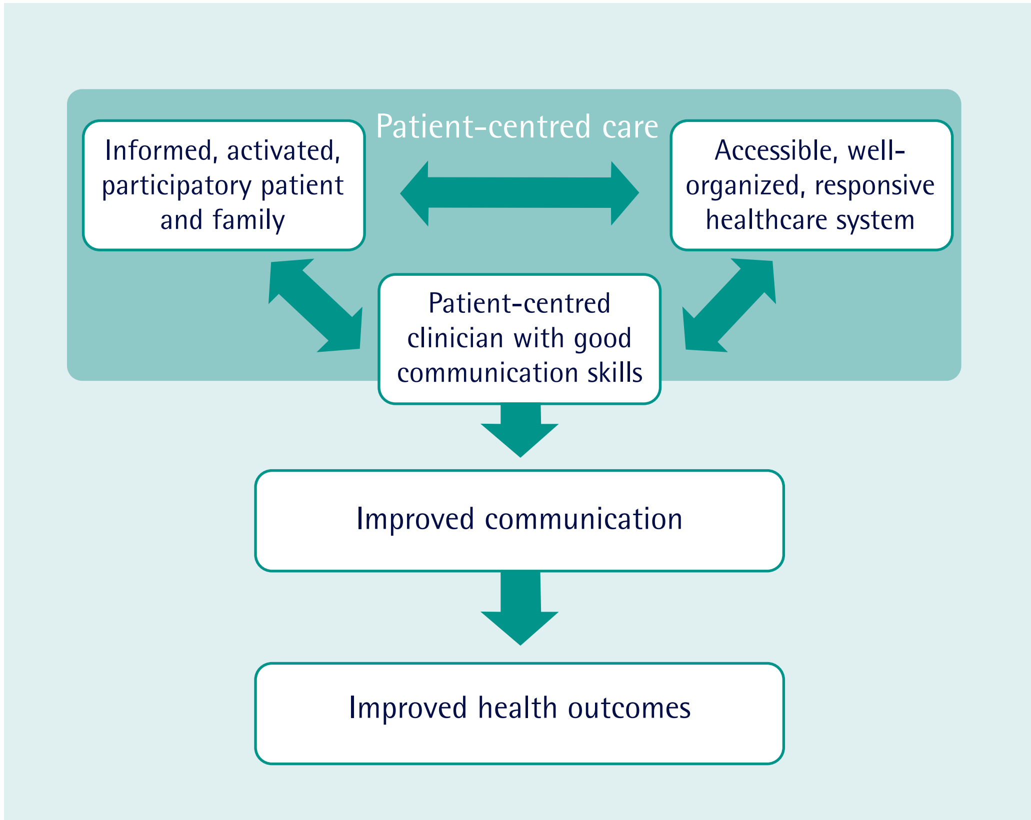

Figure 1.1 A model for patient-centred care (adapted from Abrahams et al.[2]).

quality of life (QOL) and require attention and measurement (see Chapters 2, 3 and 15). The training and skill set of the specialist oncology MDT must encompass high levels of communication skills; some team members will need advanced communication skills (see Chapter 4). The distribution of roles in the MDT will draw on different strengths to bring about a patient-centred approach. Some team members may be naturally excellent communicators; for others it will be an acquired skill. Teams should consciously plan their activities to draw on the strengths of their members. Increasingly, patient engagement and empowerment are contributing to improve the quality and outcomes of care (see Chapters 5 and 18). Primary care and the voluntary sector are vitally important in ensuring the best patient-centred care (see Chapters 6 and 7). As diagnosis and treatments improve, many more patients are surviving their cancers and require support during their periods of active treatment, as well as careful consideration of what is needed thereafter to ensure the best outcomes (see Chapters 8–12).

There is good evidence that cancer care can be delivered well when disciplines and institutions work together in an integrated way (see Chapter 13). However, we identify a series of special challenges to integrated cancer care. The first challenge is to integrate primary care and hospital care, which has been well reviewed by Rubin *et al.*[3] They concluded: 'The strengths of primary care – its continuous, coordinated, and comprehensive care for individuals and families – are particularly evident in prevention and diagnosis, in shared follow-up and survivorship care, and

in end-of-life care.' Perhaps the greatest challenge for future links to primary care will come in the development of joint informatics approaches between primary care and the hospital oncology team to support communication between the teams and with patients that will underpin speed and excellence. These developments will aid improvements in GP–oncology MDT communications that will support work on earlier cancer diagnosis, patients' whole cancer journey, and integrated hospital–community approaches to survivorship and rehabilitation (see Chapters 8–13).

Second, links between oncology and palliative care have always been central to the best patient-centred approaches; these have been reviewed recently by Hui and Bruera.[4] The integration of palliative and supportive care throughout the patient's journey will bring well-recognized benefits in terms of QOL, symptom control and patient experience (see Chapters 11 and 12). There is emerging evidence that early palliative care can be associated with improved service delivery and possibly improved survival.[5]

Third, links between oncology and geriatrics will be vitally important.[6] Cancer is a disease of older people and in the UK two-thirds of our patients are diagnosed when over the age of 65 years. In general, older people are diagnosed later, have less treatment and their cure rates are generally lower. The reasons underpinning the low uptake of major cancer treatments in older people are poorly defined, but probably include comorbidity as well as patient preference and healthcare professional biases.

Fourth, the best outcomes for patients, including the best QOL and the best experience, mean that the specialist oncology team must link with other hospital disciplines to bring in their skills during both the diagnosis and management of their patients. Modern health informatics is increasingly facilitating such links and approaches. Electronic patient records enable good communications between hospital teams to the benefit of patients (see Chapter 13).

Finally, and importantly, close liaison between psychology, psychiatry, GPs, social services and cancer specialists is essential to achieve excellent, integrated, patient-centred care.

Patient-centred care acknowledges patients' individual information needs and the need for support for both physical and psychological health. It is important to recognize and adapt patient-centred care depending on the individual patient's wishes, background, social support and physical and psychological comorbidities. Integrating with a range of other medical specialties, allied healthcare professionals and third sector providers such as charitable organizations can help tailor communication and treatment for individual patient needs.

Tools to promote patient-centred care

A substantial number of tools need to be deployed to ensure that the care of cancer patients is both excellent and patient-centred.

- Clear policy and guidance on the importance and best ways to achieve patient-centred care.[7–11] Commissioners and management models should specify patient-centred approaches.
- An emphasis on patient-centred approaches in healthcare professionals' training and in the leadership, organization and management of health services.
- Patient engagement and empowerment (see Chapter 5) are powerful sources of influence on care quality. We should consistently seek patient input. Initiatives can be 'co-produced' by patients and healthcare professionals. As we develop new policies and plans, joint working between healthcare professionals and patients, carers and advocates will ensure a patient-centred approach.[8]

- Excellence in communication training for healthcare professionals.
- Provision of ongoing holistic needs assessment and support for patients by front line healthcare professionals and appropriate engagement of specialized psychosocial oncology services and counselling.
- Modern health informatics can ensure ready communications and access to information for patients and healthcare professionals and will underpin the future of patient-centred care.
- Measuring HRQOL and PROMs in clinical practice, clinical research and population studies (see Chapter 2). Such measurements provide insights into patient well-being, experience and quality of outcome, as well as valuable quantitative feedback on the attainment of patient-centred goals. The ability to measure QOL through PROMs allows us to draw attention to these key issues and measure the impact of efforts to provide excellent patient-centred care.

Conclusion

There is a longstanding consensus that cancer care should be patient-centred and integrated and there is considerable agreement about what that means. There is recognition, however, that patient-centred and integrated care is difficult to achieve and remains incomplete, but we have powerful tools to support continued progress. The chapters and case studies in this book provide evidence, advice and guidance to help healthcare professionals achieve these aims.

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